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STANDING COMMITTEE ON LEGAL AND SOCIAL ISSUES

Inquiry into end-of-life choices

Geelong — 29 July 2015

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Ms Jill Mann, coordinator, Respecting Patient Choices program, Barwon Health.

**Necessary corrections to be notified to
executive officer of committee**

The CHAIR — I welcome our next witness, Ms Jill Mann, the Respecting Patient Choices program coordinator at Barwon Health. I caution that all evidence taken at this hearing is protected by parliamentary privilege as provided by the Constitution Act 1975 and further subject to the provisions of the Legislative Council standing orders. Therefore you are protected against any action for what you may say here, but any comments made outside the hearing are not afforded such privilege. Today's evidence is being recorded. You will be provided with proof versions of the transcript within the next week. Transcripts will ultimately be made public and posted on the committee's website. We have allowed half an hour for this session this morning. I invite you to make some opening remarks and thereafter the committee will have questions.

Ms MANN — Thank you. Firstly, Dr Charlie Corke would have liked to have been here, but he is an apology. He has a prior engagement as vice-president of the intensive care medicine board, and he had to attend a meeting today, so he is an apology.

I would just like to read a statement that addresses the components of items 1 and 3 of the terms of reference, mainly focusing on the discussion points of community and law. In reference to item 1, Barwon Health's advance care planning program provides a multi-pronged approach in providing advance care planning facilitation across all our health sectors, including the wider community. Our collaboration with Western Victoria Primary Health Network, formerly Barwon Medicare Local, and the region's general practices has seen a model of advance care planning integrated into primary care to aid initiation and commencement of conversations.

Our data demonstrates the introduction of advance care planning in general practice effectively initiates conversations in the community and actually has many bonuses, to the point where people are discussing it in their garden clubs and dinner parties. Skilled, trained advance care planning clinicians from our service — from Barwon Health — are provided to general practice through an outreach model, and it continues to have a very high referral rate from general practice. The uptake to document completion is very high in that cohort of 90 per cent. That is compared with other health referral areas of around 50 per cent or 60 per cent. It has been demonstrated through our model that when advance care planning is initiated and facilitated in general practice through routine processes — for example, over 75 health assessments — and in the absence of acute illness, in a trusted environment individuals are more likely to engage in that process. Our average referrals for the year 2014–15 have been around 120 a month, and about 95 of those go on to complete documents. That is quite high.

Practice nurses have actually expressed a very keen interest and a desire to facilitate advance care planning but really are challenged by the current funding items, unfortunately, with general practice because it is run as a private practice. Unfortunately current MBS items do not cover the reimbursement for advance care planning and therefore the services are provided by Barwon Health staff. Thankfully we have a very visionary CEO who has provided some internal funding for that to occur.

We do address public awareness through providing community and group presentations. We facilitate a number of those annually, and we also provide staff education and training, both internally and externally. We provide advance care planning training.

Processes and systems have been implemented that aid the transfer of information, although they are not perfect, through the consumer's health journey, which allows access to previously documented preferences that might have been completed in the community in a 'well' phase, which can then inform at each intersection with healthcare providers. However, there are concerns within our local community about the legal weight of common-law documents, such as a statement of choices, particularly when the individual is not wanting certain medical interventions. I have a couple of quotes from consumers, if I can share those with you. The first one is:

I think the refusal of treatment (certificate) should always be offered to those with very strong views on not wanting intervention.

The second is:

As the ambos are often first on the scene they must access our ACPs and wishes before attending. I have heard of attempting CPR on those who have stated to wives and husbands of not wanting CPR but they have not even asked the partner in the home and commenced same. And God help us who live alone. This must be addressed, it terrifies me.

Just so you know, we do routinely provide advance care planning documentation to Ambulance Victoria where there is a preference for not having life-saving or life-prolonging interventions. That, again, is not a perfect system. It is around a location of interest rather than a person.

Regarding advocating for the individual — and I am really talking about the medical enduring power of attorney appointment here — there is, I think, a real need for appointed persons to be offered training and resources on really how to best equip them in that role, because it is a very important role they are appointed to.

That really brings me to item 3, around the legislation. We believe our current Victorian legal framework for advance care planning is probably one of the best, if not the best, in Australia, frankly, but we do recommend a legislative change around consideration to amend the Medical Treatment Act regarding the refusal of treatment certificate, which includes schedules 1 and 3 for both competent and non-competent persons. That is to remove the current limitation around a current condition. Based on our extensive experience, we believe that the act is a little bit remiss in that it does not often acknowledge the frail and elderly who may wish to exercise their autonomy to refuse treatments in all circumstances but actually may not have a current condition diagnosed.

Advisory documents require really obligatory consideration when determining medical treatment, so it really would be ideal to provide a standard of care legislatively around advance care planning documents as evidence, with clear statement of the obligations of treating doctors in respecting that person's autonomy. I think there is a bit of confusion still at the moment, and when there is confusion on the legalities and obligations regarding the person's stated preferences the result is distress for all parties concerned, including treating medical officers, care staff, families and the consumers. There can be devastating or lasting effects when a consumer's preferences are not known or are ignored totally.

I guess the biggest risk for us as a program is that we are internally funded to provide the service, and if that were to stop tomorrow, then our good work would stop. I do have some handouts of our activity to demonstrate how the community has actually been engaged, and consumer engagement has been very successful.

The CHAIR — Thank you, Ms Mann, for that opening presentation and for your suggested recommendations to the committee. If I could just ask the first question and go to your suggestion that the Medical Treatment Act not be confined to a current condition, can you perhaps just give a bit more background to, in practice, what you and your colleagues see?

Ms MANN — Yes, certainly. With refusal of treatment certificates, they are a tool of the Medical Treatment Act — a legislative document. Only certain people who have a current diagnosed condition can complete one of those. So if I am diagnosed with cardiac disease, I can refuse treatment for any interventions for that particular condition. However, if I develop something else, it is not covered. So at the age of 84 I might decide that I do not actually want CPR, knowing full well about the outcomes and so forth, but I cannot refuse it if I do not have a current condition. So it is a limitation we have found through our program — that we cannot offer that little bit of extra insurance to people who are very adamant about refusing certain interventions that they do not feel are warranted.

Ms SPRINGLE — I am curious for you to unpack the issue of emergency services ignoring the wishes of people who have decided they do not want treatment. Could you give us a bit more detail around that?

Ms MANN — Yes. It is usually around people being confused — medical staff and health professionals being confused about what their obligations are. Of course they are trying. The medical approach is to save life at all costs, generally, and that is what they are trying to do, so it is very hard to switch. Where there are absolutely clear instructions, maybe in a directive sort of form, they are not usually ignored, but where there is an advisory document around a statement of wishes and outcome — if my outcome is likely to be poor, and I describe that and unpack that in the document — it is often not really unpacked at the point of needing life prolonging interventions point. It just needs a discussion — a good interpretation of that document for this condition. I think if we could have some more robust suggestions around how that can be in place and support doctors to make those decisions based on prior evidence.

Ms PATTEN — Just following quickly on from that, I have noticed that what we are seeing, certainly in metropolitan areas, is that first responders are not the ambos. The first responders are very often the fire brigade, so they are quite often providing, first, CPR specifically, and then the ambos will come in and provide more

detailed treatment. Can you see a technological way that the patient's wishes can be known by whoever turns up at that door, whether it is the ambos, the GPs, the fire brigade?

Ms MANN — That would require a very integrated system I am assuming. I guess a good start would be to have an Australia-wide register of someone who has actually made some decisions about their treatment, such as like an organ donation register, which is a similar thought process. We do through our service provide little wallet cards, but that means someone has to look in a wallet. Technologically it would mean our emergency service systems would have to be integrated, and it would have to be better than a location-of-interest alert; it would have to be a personal alert. What we do advise people is to keep their advance care plan very handy so that everyone else knows where it is, so it can be easily accessed if in an emergency it is required. The other thing is we also try to encourage our consumers, whoever is making the call, to say such and such has an advance care plan and give just a brief description of what is in it — 'wants all treatment, 'doesn't want certain treatment', that sort of thing — so the call centre can refer that information. But as far as a technological solution, I am not quite sure, unless we are all microchipped maybe or something and they ran a scanner over us!

Ms PATTEN — Can we strike that?

Ms MANN — But, honestly, it would have to be a very intricate integrated system for that to occur.

Mr MELHEM — I think the microchip is available for 200 bucks, from watching TV the other night. Does the current legislation balance the opposing principles of sanctity of life and individual autonomy? Is it balanced there?

Ms MANN — I think it is probably relatively balanced. It is just that it is complex and individuals are all different, so it is hard to apply a law to such different individuals, I guess. We have quite well younger people who have certain beliefs and really are adamant that life is not to be saved at all costs, even in the absence of an illness. So yes, sanctity of life, is a very individual thing, I think. It is tricky to balance it, but I think for our purposes we have to be very consumer centred. We are documenting a person's preferences, not in isolation, we are engaged with their doctors, obviously, as well.

Mr MELHEM — So you are saying if it is clearly documented, that could take away doctors trying to save life, regardless of their religious beliefs, and that is what they are trying to do. That does sort of take the pressure away from doctors; it is clearly the wish of the patient. You are saying documentation, education, perhaps legislation could assist in that. What if an individual changes their mind? The young person you talked about could change their mind when the time comes — 'I am not ready yet'. What is your experience?

Ms MANN — Yes, people do change their minds. We actually have a review process built into our service to ensure they are as up-to-date as they can possibly be, I do not know that many other programs actually have that facility. We try to keep in touch with people. We never close off referrals, that sort of thing, so that we try to keep their documentation as up-to-date as possible. Every intersection with the health service should prompt a review of that document, yes.

Ms FITZHERBERT — A lot of the discussion we have had in the hearings has been about end-of-life issues for the very elderly or seriously ill, but I am interested in your views as to whether we adequately provide palliative care for paediatrics and young people — just any thoughts you may have on that.

Ms MANN — I honestly cannot comment because we do not facilitate advance care planning for children. We do for adults. Most of the children requiring that might be linked in with Royal Children's, who do advance care planning for children. Ours is very much an adult program, so I cannot actually comment. I would love to sidetrack and have a look at what we could do for our children in our community, definitely.

Ms FITZHERBERT — Sure, I understand the role here, but I just wondered if you had any observations that you would care to give.

Ms MANN — No, because I am not in touch with children and not involved in the paediatrics ward, so I cannot comment, I am sorry.

Ms PATTEN — With a lot of the advance care planning it seems to be very much around refusal of treatment and withdrawal of treatment. Do you think that there is room for a more proactive approach, and for a person to say that, ‘Not only do I want to refuse these treatments but this is what I want to happen. I want you to up my sedation’ — or whatever it is — ‘in these circumstances’?

Ms MANN — Definitely. In fact I would say the majority of our advance care planning conversations do not end up in a refusal of treatment. It is usually about what is important for that person to live well, based on their values. And it is more about, ‘In certain situations what sort of things would you want to have happen? What is paramount for you, and what matters most? What is the thing that matters most to you of all things at that time?’. Those are the sort of things we try to capture. It is not just about not having a certain intervention.

Ms PATTEN — That is right, and I think this came up in one of the other hearings last week — that you would be having this conversation around the television with your family and parents, and your mother might look at the television and say, ‘God, I never want to be that person in the corner of the nursing home being spoonfed’. They are not dying from being in the corner, but that is when they probably want a more active end. Is that something that fits into your planning now — an active end which is — —

Ms MANN — In so far as we can help people be clear about when they would not want their life prolonged, so therefore they may not even want antibiotics at that point if they are in a corner of a nursing home being spoonfed. Yes, we do write things about that. We have a discussion that it is easier sometimes not to start some treatments than actually to stop them, so we have those sort of discussions. It can be very much around, ‘If I end up like that, that is enough’, but also I think people need some comfort in that we will provide as much as we need to to make them comfortable. It is not about assisting or hastening death, it is about making sure that they are living as comfortably as they possibly can, and this process can actually give them a lot of confidence in that they can say, ‘I’m happy to be sedated; I don’t want to know about it’ — that sort of thing. They can say that in their plans, yes.

The CHAIR — By way of the final question, you talked before about you are running this program basically because the CEO has made some resources available and it is not a system-wide program. Can you talk about how you came to put your program together and whether you collaborated with other colleagues and other health service providers?

Ms MANN — Yes, certainly. We have worked closely with Austin Health — Bill Silvester’s team there — in the past. We morphed — we were quite different. They were very acute focused, and we did see that this would sit well in the community, and that is why we were placed in the community quite early. I was employed in 2005 to implement advance care planning for Barwon Health, and that was just me. Since then we have realised that more human resources have been needed.

We had a very focused group that we were looking to do advance care planning for: palliative care, aged care, chronic illness. Renal dialysis service was one group. What we found very early on is those people did it to varying degrees of uptake, but their spouses all wanted to engage in advance care planning too, and then that rippled off to other family members. We found we had this group that we called external to our focus area and that had a very high completion rate. We thought, ‘Why are we settling for just advance care planning with this cohort’ that we know are the more urgent requirement, but let us get a community groundswell happening. We had a community launch back then and then engaged with our Medicare Local GP network, which is now the health network. We have worked with them collaboratively on a number of initiatives to help get advance care planning into general practice and part of a routine core business.

That is really how that has happened, but we have not ignored our group that we first identified. We still focus on the chronically unwell or people with life-limiting illness, and we have trained facilitators in those areas to help have those conversations as well. So it is quite a multipronged approach, and I think here in Geelong we are quite blessed because of the geographics. Our little office is the central hub of all things advance care planning, and it all comes into us. We can audit and we can create alerts and things like that, so it helps it to be much more integrated, I think, than you could get in a metropolitan area. But there are certainly things that we could do that you could perhaps duplicate in an area.

The CHAIR — Ms Mann, the committee thanks you very much for your evidence this morning and for your preparedness to answer our questions. Thank you for the information.

Ms MANN — Thank you.

Witness withdrew.